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Human rights bodies and mechanisms

Study on the implementation of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members

Report of the Human Rights Council Advisory Committee

I. Introduction

1. In its resolution 29/5, the Human Rights Council requested the Advisory Committee to undertake a study to review the implementation of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, together with the obstacles thereto, and to submit a report to it at its thirty-fifth session containing practical suggestions for the wider dissemination and more effective implementation of the principles and guidelines in order to eliminate discrimination and stigma associated with leprosy and to promote, protect and respect the human rights of those affected by leprosy and their family members. The Council encouraged the Advisory Committee, when elaborating the report, to take into account the views of Member States, as appropriate, relevant international and regional organizations, including the World Health Organization (WHO) and the Office of the United Nations High Commissioner for Human Rights (OHCHR), relevant special procedures, national human rights institutions and non-governmental organizations (NGOs), as well as the work done on the issue by relevant United Nations bodies, specialized agencies, funds and programmes within their respective mandates.

2. Throughout history, leprosy has been one of the most feared and misunderstood diseases. One of the major reasons for the stigma and discrimination directed against persons affected by leprosy and their family members is the deep-rooted misconception, both in the past and today, of leprosy, despite it being one of the least contagious human transmissible diseases. In the past, the lack of scientific knowledge of the causative organism of the disease, its mode of transmission and lack of effective remedy contributed to the stigma and discrimination against persons affected by leprosy and their family members. Many countries pursued policies that isolated persons affected by leprosy, such as quarantine, forced hospitalization and the establishment of leprosariums, which were maintained even when it was scientifically and medically proven that the disease was completely curable and not easily transmissible, thereby reinforcing stigma and

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discrimination and depriving persons affected by leprosy and their family members of the enjoyment of their fundamental human rights and dignity and reintegration into society.

3. With the introduction of multidrug therapy in the late 1980s, there is now an effective cure for leprosy. Since 1995, WHO has been supplying multidrug therapy free of charge to persons affected by leprosy in all endemic countries. Availability of drugs has allowed countries to focus their efforts on eliminating leprosy (defined as a prevalence rate of less than 1 case per 10,000 population) as a public health problem and on further reducing the leprosy burden post-elimination. Treatment with standard WHO multidrug therapy renders patients non-infectious within a few days. Since the mid-1980s, the global prevalence of leprosy has decreased from more than 5 million to less than 200,000 in 2015, and some 16 million people have been cured of the disease since the introduction of multidrug therapy. Nonetheless, although leprosy is no longer a major public health problem in most countries today, several millions of people affected by the disease worldwide continue to experience stigmatization and discrimination.

4. Within the international human rights system, concern regarding discrimination against persons affected by leprosy and their family members was initially expressed by the Sub-Commission on the Promotion and Protection of Human Rights at its fifty-sixth session in 2004. In its resolution 2004/12, the Sub-Commission requested its member, Yozo Yokota, to prepare a preliminary working paper on the issue[1] to be submitted to the Sub-Commission at its fifty-seventh session. In the paper, persisting discrimination against persons affected by leprosy and their family members was highlighted, including in relation to employment, marriage, education, use of public places, such as hotels and restaurants, and means of transportation.

5. The Sub-Commission's work was discontinued owing to the reform of the United Nations human rights system in 2006. In 2008, the Human Rights Council took up the issue and noted the work already done by the Commission on Human Rights and the Sub-Commission. In its resolution 8/13, the Council requested OHCHR to collect information on the measures taken by Governments to eliminate discrimination against persons affected by leprosy and their family members and to hold a meeting to exchange views among relevant actors, including Governments, observers of the United Nations, relevant United Nations bodies, specialized agencies and programmes, NGOs, scientists, medical experts as well as representatives of persons affected by leprosy and their family members. In the same resolution, the Council requested the Advisory Committee to examine the report prepared by OHCHR and to formulate a draft set of principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members and to submit it to the Council for consideration by September 2009.

6. At its third session in August 2009, the Advisory Committee adopted the draft set of principles and guidelines, taking into account the report of OHCHR,[2] and submitted it to the Human Rights Council for consideration at its twelfth session in September 2009. In its resolution 12/7, the Council again requested OHCHR to collect the views of relevant actors including Governments, observers of the United Nations, relevant United Nations bodies, specialized agencies and funds and programmes, NGOs, scientists and medical experts, as well as representatives of persons affected by leprosy and their family members, on the draft principles and guidelines, and to make those views available to the Advisory Committee.

7. The Advisory Committee adopted the revised draft set of principles and guidelines at its fifth session in August 2010, and submitted it to the Human Rights Council at its fifteenth session in September 2010.[3] In its resolution 15/10, the Council took note with appreciation of the revised draft and invited the General Assembly to consider, as appropriate, the issue of discrimination against persons affected by leprosy and their family members, including possible ways to promote the principles and guidelines.

8. In December 2010, the General Assembly adopted resolution 65/215, in which it took note with appreciation of the principles and guidelines and encouraged Governments,

[1] E/CN.4/2005/2-E/CN.4/Sub.2/2004/48, p. 35.
[2] A/HRC/10/62.
[3] A/HRC/15/30, annex.

relevant United Nations bodies, specialized agencies, funds and programmes, other intergovernmental organizations and national human rights institutions to give due consideration to them in the formulation and implementation of policies and measures concerning persons affected by leprosy and their family members. The Assembly also encouraged all relevant actors in society, including hospitals, schools, universities, religious groups and organizations, business enterprises, newspapers, broadcasting networks and NGOs, to give due consideration, as appropriate, to the principles and guidelines in the course of their activities.

9. In response to the Human Rights Council's request in resolution 29/5, the Advisory Committee, at its fifteenth session in August 2015, established a drafting group composed of eight experts: Laurence Boisson de Chazournes, Laura-Maria Crăciunean-Tatu, Mario Luis Coriolano, Kaoru Obata, Ahmer Bilal Soofi, Yishan Zhang, Changrok Soh and Imeru Tamrat Yigezu. Xinsheng Liu and Obiora Chinedu Okafor joined the drafting group subsequently. The Chair of the group was Mr. Obata and the Rapporteur was Mr. Yigezu.[4] The Advisory Committee requested the drafting group to submit a preliminary report to it at its sixteenth session, taking into account the replies to the questionnaire that had been sent to States, national human rights institutions, international organizations, United Nations agencies, relevant treaty bodies and special procedures as well as international and national NGOs.

10. The Advisory Committee took note of the drafting group's preliminary report at its sixteenth session in February 2016, and requested the drafting group to recirculate the questionnaire to stakeholders who had not responded, in order to allow for more informed work. It stated that additional replies from States and national human rights institutions were especially welcome. The Advisory Committee also requested the drafting group to submit a progress report to it at its seventeenth session.

11. At its seventeenth session, the Advisory Committee took note of the progress report submitted by the drafting group and requested it to submit the draft final report at its eighteenth session, with a view to submitting the final report to the Human Rights Council at its thirty-fifth session.

12. A total of 57 responses to the questionnaire were received from 12 States, 9 national human rights institutions, 1 international organization and 35 international and national NGOs.[5] No responses were received from special procedures and treaty bodies. The

[4] The drafting group would like to thank Nathaniel Melaku, Faculty of Law, Addis Ababa University, Ethiopia, Izevbuwa Ikhimiukor, Osgoode Law School, York University, Toronto, Canada, and Yozo Yokota, Director, Center for Human Rights Affairs, Japan, for their valuable research input to the study. It also thanks the Nippon Foundation for facilitating the gathering of crucial information and its continued support during the preparation of the report, the International Federation of Anti-Leprosy Associations for facilitating responses from national associations of persons affected by leprosy and for providing inputs to the study; and, in particular, Yohei Sasakawa, Chair of the Nippon Foundation and WHO Goodwill Ambassador for the elimination of leprosy and ending stigma and discrimination against persons affected by leprosy who, from the outset, initiated action on the issue within the international human rights mechanisms.

[5] Responses were received from Bahrain, Brazil, Chile, El Salvador, Estonia, Japan, Montenegro, Qatar, Saudi Arabia, Thailand, the United States of America and Viet Nam; the national human rights institutions of Algeria, Denmark, Egypt, India, Montenegro, Rwanda, Serbia, the United Republic of Tanzania and Venezuela (Bolivarian Republic of); as well as World Health Organization, Nippon Foundation, Sasakawa Memorial Health Foundation, International Association for Integration, Dignity and Economic Advancement (IDEA), IDEA-India, The Leprosy Mission International-Bangladesh, The Leprosy Mission-Netherlands, Netherlands Leprosy Relief-Brazil, Movement for the Reintegration of Persons Affected by Hansen's Disease (MORHAN) (Brazil), Social Corporation for the Rehabilitation of Persons Affected by Hansen's Disease and their Family (CORSOHANSEN) (Colombia), Federation of Associations of Persons Affected by Hansen's Disease (FELAHANSEN) (Colombia), Ethiopian National Association of Persons Affected by Leprosy (ENAPAL) (Ethiopia), Fondation Kalipa pour le développement (FOKAD) (Democratic Republic of the Congo), Gerakan Peduli Disabilities and Lepra Indonesia (GPDL) (Indonesia), FAIRMED Foundation (Sri Lanka), Zen-Ryo-Kyo National Hansen's Disease Sanatoria Residents' Association (Japan), HANDA Rehabilitation and Welfare Association (China), The Leprosy Mission-Myanmar, Fontilles-India, Lepra-Bangladesh, Fontilles-Nicaragua, The Leprosy Mission-Niger, The Leprosy Mission-Nepal, Lepra Society-India, International Federation of Anti-Leprosy Associations (ILEP) (India),

majority of the responses from States came from countries in which leprosy was not endemic.

13. Two members of the drafting group, Mr. Okafor and Mr. Soh, participated in the international conference entitled "Towards holistic care for people with Hansen's disease, respectful of their dignity", held in Rome in June 2016,[6] where, they had the opportunity to discuss and hear, first hand, the testimonies of persons affected by leprosy and obtained relevant feedback on the measures that they expected their Governments to take for the effective implementation of the principles and guidelines. The information gathered at the conference is reflected in the present report.

II. Summary of the contents and status of the principles and guidelines

A. Summary of the contents of the principles and guidelines

14. The principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members[7] consist of two parts. The first part, "Principles", recognizes the basic human rights of persons affected by leprosy and their family members, which are already enshrined in the Universal Declaration of Human Rights and in other relevant international human rights instruments such as the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and the Convention on the Rights of Persons with Disabilities. The second part, "Guidelines", translates the principles into concrete action and provides for States' responsibility to respect, promote, protect and ensure the full realization of all human rights for all persons affected by leprosy and their family members. The principles and guidelines are designed to meet the specific needs of persons affected by leprosy and their family members and ensure them the rights that are or may be denied to them in countries globally.

15. Principle 1 reaffirms the right of persons affected by leprosy and their family members to be treated with dignity and their entitlement to all the rights specified in international human rights instruments. Principle 2 provides for non-discrimination against persons affected by leprosy and their family members on the grounds of having or having had leprosy. Principle 3 enunciates that persons affected by leprosy and their family members have the same rights as everyone else with respect to marriage, family and parenthood, while principles 4 and 5 stipulate that those affected by leprosy have the same rights as everyone else to full citizenship, identity documents and participation in public and political life. Principle 6 provides for the right to employment on an equal basis with others and the right to work in an inclusive environment, while principle 7 provides for the right to education and other training. Principle 8 stipulates that persons affected by leprosy and their family members are entitled to the fullest development of their human potential and to the full realization of their dignity and self-worth, while principle 9 provides for persons affected by leprosy and their family members to have the right to active involvement in decision-making processes regarding policies and programmes that directly concern their lives.

16. The "Guidelines" set out the actions that States should take to implement the principles and is divided into 14 sections. Guideline 1 sets out the general obligations of States in relation to the realization and protection of the rights of persons affected by

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Netherlands Leprosy Relief-Mekong (Viet Nam), The Leprosy Mission-England and Wales, The Leprosy Mission-Chad, IDEA-Nepal, Marcial Escobar on behalf of an NGO (Paraguay), International Federation of Anti-Leprosy Associations (ILEP) (Paraguay), The German Leprosy and Tuberculosis Relief Association (DAHW) (Sierra Leone), Persatuan Mandiri Kusta (PerMaTa)-National (Indonesia), PerMaTa-South Sulawesi (Indonesia), YPPCK Leprosy and Disability Care Foundation Java (Indonesia) and SOLE (Angola).

[6] The conference was jointly organized by the Pontifical Council for Health Care Workers, Good Samaritan Foundation and the Nippon Foundation, in cooperation with the Foundation Raoul Follereau, the Sovereign Order of Malta and Sasakawa Memorial Health Foundation.

[7] A/HRC/15/30, annex.

leprosy and their family members, including implementation of legislative, administrative and other measures to address laws, polices, customs and practices that discriminate against or forcefully segregate persons affected by leprosy and their family members; ensuring that authorities and institutions take steps to eliminate discrimination against persons on the grounds of leprosy; taking measures to ensure the full realization of the rights set out in the different human rights instruments; and consulting with and actively involving persons affected by leprosy and their family members in decision-making processes that concern them. Guideline 2 provides for equality and non-discrimination in relation to legal protection and the law, while guideline 3 provides for protection of the human rights of women, children and other vulnerable groups affected by leprosy. Guideline 4 promotes reunification of family members separated as a result of policies and practices relating to leprosy, while guideline 5 requires States to promote the full inclusion and participation of persons affected by leprosy and their family members in the community, ensure that they are not isolated or segregated from the community, provide social support to facilitate reintegration into the community and ensure their access to housing of their choice, including in leprosariums and hospitals, if they so wish.

17. Guideline 6 reinforces principle 5 and calls upon States to ensure that persons affected by leprosy and their family members enjoy the right to participate in the political process and to facilitate their access thereto, while guideline 7 emphasizes support for employment, including self-employment, the formation of cooperatives and vocational training. Guideline 8 elaborates on principle 7 regarding the right to education, while guideline 9 requires States to remove discriminatory and derogatory language, such as the term "lepers", from government publications. Guideline 10 encourages States to ensure access for persons affected by leprosy and their family members to public places, public transport, recreational and cultural facilities and places of worship. Guideline 11 requires States to provide persons affected by leprosy access to health care on an equal basis with others, institute early detection programmes and ensure prompt treatment of leprosy, include psychological and social counselling in standard care and ensure access to free medication. Guideline 12 provides for the economic, social and cultural rights of persons affected by leprosy and their family members, such as an adequate standard of living, financial assistance, as necessary, education and vocational training. Guideline 13 focuses on awareness-raising throughout society to foster respect for the rights and dignity of persons affected by leprosy through various means and media. Finally, Guideline 14 recommends that States establish a committee to coordinate activities relating to the rights of persons affected by leprosy and their family members and include information on policies and measures taken to end discrimination against persons affected by leprosy and their family members in their reports to the relevant treaty bodies.

B. Status of the principles and guidelines

18. The principles and guidelines build upon and essentially restate the core principles of international human rights law. Noted with appreciation by both the Human Rights Council and the General Assembly, they constitute the standard to be upheld by States in assuming their responsibility to prohibit all forms of discrimination against persons affected by leprosy and their family members.

19. The goal of the principles and guidelines is to ensure full respect for and full realization of all human rights of persons affected by leprosy and their family members. This goal is critical for every society in order to reaffirm the common faith enshrined in the Charter of the United Nations "in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women and of nations large and small". The global commitment to human rights cannot be achieved if the rights of any particular group of people, such as persons affected by leprosy and their family members, are not fully respected or protected. Thus, even assuming that the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members are not legally binding on States, they nonetheless constitute persuasive authority with regard to States' practices to ensure the right to non-discrimination of persons affected by leprosy and their family members. In general terms, it could be underlined that aspects of the principles and guidelines are binding on States that have ratified human rights treaties with similar obligations.

III. Review of the implementation of the principles and guidelines

20. This section is mainly based on the responses provided by States, national human rights institutions and national and international NGOs [8] to the questionnaire on the elimination of discrimination against persons affected by leprosy, which form the main basis for the review of steps taken to date by States and other stakeholders towards the wider dissemination and more effective implementation of the principles and guidelines. The main thematic components of the principles and guidelines provided the basis for the review.

21. An overwhelming number of responses came from national and international NGOs, in particular associations of and organizations working with persons affected by leprosy and their family members. As mentioned earlier, relatively few responses were received from States and national human rights institutions and most of them, particularly those from States, were from non-endemic countries. Nonetheless, the responses received from organizations of persons affected by leprosy and international NGOs provided a more or less full picture of the positive measures taken by the States concerned and the gaps that need to be addressed in order to achieve the effective implementation of the principles and guidelines.

A. Awareness-raising and dissemination of the principles and guidelines

22. The responses received so far revealed that States had not yet developed comprehensive policies and action plans involving both government and non-government stakeholders to raise awareness about leprosy with a view to overcoming the stigma and discrimination towards persons affected by leprosy and their family members, including awareness-raising about and dissemination of the principles and guidelines. However, a number of States had taken several positive steps in that regard.

23. In terms of more systematic and coordinated awareness-raising about leprosy and dissemination of the principles and guidelines, the Government of Japan has played a prominent role. Key points of the principles and guidelines have been translated into Japanese and posted on the website of the Ministry of Foreign Affairs.[9] The human rights section of the Ministry of Justice has undertaken public awareness activities on the principles and guidelines in the form of parent-child symposiums on Hansen's disease, with the participation of students as panellists. The Ministry also distributed brochures on the principles and guidelines in Japanese, which had been prepared by the Centre for Human Rights Education and Training (a non-profit organization) and also posted on its website.[10] The Ministry of Health, Labour and Welfare organized various symposiums on leprosy and distributed brochures entitled "Hansen-byo no Mukogawa" (the other side of Hansen's disease) to schoolchildren, which provided facts about leprosy and information on the forcible isolation of persons affected by leprosy in the past. The Ministry of Education, Culture, Sports, Science and Technology called upon medical schools across Japan to provide accurate medical knowledge about leprosy. Several museums have been established and the 13 national sanatoriums in Japan also served as important centres of information on leprosy and reminders of the country's past experience of discriminatory practices against persons affected by leprosy and their family members. Zen-Ryo-Kyo, the National Hansen's Disease Sanatoria Residents' Association, considered that the Government of Japan had made efforts to raise as much awareness as possible on leprosy at both the national and local levels.[11]

24. Other States have also taken positive steps to raise awareness about leprosy and to disseminate the principles and guidelines, although those activities seemed to have been undertaken sporadically or to be limited to certain sectors of society. Such awareness-raising activities aimed at promoting non-discrimination against persons affected by leprosy

[8] Some of the responses received are not reflected in the present report, as they were not available in English.

[9] Responses from Japan and the Nippon Foundation.

[10] Ibid.

[11] Ibid and Zen-Ryo-Kyo.

have been undertaken through national leprosy programmes (or equivalent) run by Ministries of Health and by national human rights institutions and focused mainly on training health workers and providing education to local communities. The principles and guidelines have been disseminated in print form, through electronic media and in workshops and annual events, such as World Leprosy Day.[12]

25. Most of the activities to raise awareness and disseminate the principles and guidelines, including translation into local languages, had been undertaken by associations of persons affected by leprosy in their respective countries. However, it was pointed out that such awareness-raising activities, including the use of the principles and guidelines as a standard, were far from adequate or were limited to certain sectors of society. Many NGOs indicated that there were few or no visible policies or action plans prepared by their respective Governments to raise awareness specifically about leprosy or to disseminate the principles and guidelines, although there might be policies and strategies in place for promoting non-discrimination in general or towards specific groups — such as persons with disabilities — which might also apply to persons with disabilities who were also affected by leprosy.[13]

26. With respect to non-endemic countries or countries with few leprosy cases, although most of them were aware of the principles and guidelines, there was no practical necessity to take any particular action, mostly owing to the favourable epidemiological situation regarding leprosy in those countries.

B. Participation and consultation in decision-making processes

27. The responses received showed that some States had taken certain positive steps towards enabling persons affected by leprosy to consult on issues that affected them and to participate in decision-making processes on such issues.

28. In Japan, the Ministry of Health, Labour and Welfare held annual conferences on measures to be taken regarding Hansen's disease. At the conferences, persons affected by leprosy gave advice on issues that concerned them as well as suggestions on how to improve policies already in place. The Ministry took into account the outcomes of the discussions at the annual conferences when formulating other policies and laws.[14] The 2009 Act on Promoting the Resolution of Hansen's Disease Issues specifically states that the Government shall take the necessary measures to reflect the opinions of persons affected by Hansen's disease and other relevant persons in the formulation and implementation of measures concerning persons affected by leprosy as well as the establishment of forums for consultation.

29. In India, organizations of persons affected by leprosy had a strong voice and were invited by relevant government authorities to meetings concerning them at the district, state and national levels. Those organizations had influenced government policies and measures to a certain extent but still had a long way to go. Self-help groups had been formed, peer group discussions had been held and local communities decided on the support required by persons affected by leprosy. There was better participation of persons affected by leprosy in discussions on issues concerning them among organizations working in the field.[15]

30. In Brazil, MORHAN was a strong force at the national level. It often had a seat on the National Health Council and participated actively in national, state and municipal health conferences. The organization undertook evaluations every three years of government promises concerning the human rights and health care of persons affected by leprosy and had noted more openness on the part of the Government with regard to policy and

[12] Reponses from Saudi Arabia and from the national human rights institutions of Egypt, India, Rwanda, the United Republic of Tanzania and Viet Nam.

[13] Responses from GPDL (Indonesia), FOKAD (Democratic Republic of the Congo), FAIRMED Foundation (Sri Lanka), ENAPAL (Ethiopia), HANDA (China), Fontilles-Nicaragua and The Leprosy Mission-Myanmar.

[14] Responses from Japan, the Nippon Foundation and Zen-Ryo-Kyo.

[15] Responses from the National Human Rights Commission (India), Lepra Society-India and ILEP (India).

legislative matters. However, the political platform for consultation and participation at the national level was still not adequate.[16]

31. The majority of the responses from NGOs representing persons affected by leprosy indicated that, to date, there had been minimal or no consultation with and participation by persons affected by leprosy in the government decision-making process on issues concerning them. However, they themselves had formed self-help groups and were involved in local-level advocacy and projects that affected them.[17]

C. Civil and political rights

32. All of the responses received invariably indicated that the Constitutional provisions in the respective countries provided for the enjoyment of civil and political rights by all citizens without discrimination, including persons affected by leprosy and their family members. However, a significant number of responses, particularly from associations of persons affected by leprosy and international NGOs representing them in the respective countries, indicated that, in practice, the exercise of civil and political rights by persons affected by leprosy still left much to be desired and, in some cases, was curtailed by subsidiary laws.

33. In India, the right to stand for elections was curtailed under six municipal and Panchayati Raj (local) acts in the states of Rajasthan, Andhra Pradesh, Odisha, Chhattisgarh and Madhya Pradesh. This was corroborated by a decision passed by the Supreme Court of India in 2008, which upheld the decision of a lower court that had disqualified a person affected by leprosy from contesting civic elections or holding municipal office by citing discriminatory provisions against persons affected by leprosy in a 2005 Odisha Municipal Act.[18] Moreover, although persons affected by leprosy had legal rights to citizenship and to vote, in practice, it was not easy for those living in leprosy colonies to exercise those rights since most of them could not obtain a national identity card as proof of residence because they did not have rights to the land and houses they lived in.[19] A similar concern was pointed out in Myanmar, where a high proportion of persons affected by leprosy and with moderate or severe disabilities did not have national identity cards, which was an obstacle to their exercising their right to vote.[20]

34. Many of the responses from associations of persons affected by leprosy indicated that, although their civil and political rights were constitutionally guaranteed and some governments had formulated policies in that respect, the actual exercise of those rights by persons affected by leprosy was made difficult owing to the persistent stigma and discrimination existing in society, in particular against persons with visible deformities.[21] One case that stood out was of a man affected by leprosy in Brazil who was denied a voting card by the registration officer because he was illiterate and required the officer's assistance to affix his fingerprint.[22] Most of the NGOs underlined the need for Governments to take specific policy and legal measures to ensure the full enjoyment of civil and political rights by persons affected by leprosy.[23]

35. Brazil has a wide range of legislation to ensure the enjoyment of human rights by persons affected by leprosy. The independent Public Prosecutor's Office was often called upon in cases of violation of human rights against persons affected by leprosy. In many

[16] Responses from MORHAN (Brazil) and Netherlands Leprosy Relief-Brazil.

[17] Responses from FAIRMED Foundation (Sri Lanka), FOKAD (Democratic Republic of the Congo), HANDA (China), GPDL (Indonesia), Marcial Escobar (Paraguay), The Leprosy Mission-Myanmar, CORSOHANSEN (Colombia), FELAHANSEN (Colombia), The Leprosy Mission-Nepal, IDEA-Nepal, Lepra-Bangladesh and ENAPAL (Ethiopia).

[18] Response from The Leprosy Mission Trust (India).

[19] Ibid.

[20] Response from The Leprosy Mission-Myanmar.

[21] Responses from Lepra-Bangladesh, Netherlands Leprosy Relief-Mekong (Viet Nam), Netherlands Leprosy Relief-Brazil, MORHAN (Brazil), ILA (Paraguay), The Leprosy Mission-Bangladesh.

[22] Response from Netherlands Leprosy Relief-Brazil.

[23] Responses from HANDA (China), The Leprosy Mission-Bangladesh, GPDL (Indonesia), FOKAD (Democratic Republic of the Congo), Fontilles-Nicaragua and FELAHANSEN (Colombia).

states, MORHAN and members of the International Federation of Anti-Leprosy Associations (ILEP) had created partnerships with the Ministry of Justice to not only review individual cases of violation of rights of persons affected by leprosy, but also to ensure that public policies and laws relating to Hansen's disease were upheld by the Government.[24]

D. Economic, social and cultural rights

36. Most of the responses indicated that the enjoyment of economic, social and cultural rights by all citizens, including persons affected by leprosy and their family members, was provided for in the respective Constitutions, as well as in policies, guidelines and laws of some countries. However, many NGOs indicated that several core human rights were violated in practice. They cited specific cases of violations of the economic, social and cultural rights of persons affected by leprosy, such as the right to marriage and to found a family; the right to education; the right to work; the right to access public services; the right to adequate health care; and the right to participate in political, social and cultural life owing to the prevalent and institutionalized stigma and discrimination that existed in different sectors of society.

37. With regard to the right to found a family in Nepal, examples were given of two women who were forced to leave their homes and families after being diagnosed with leprosy.[25] One respondent from Nepal stated that he was forced to sign a divorce paper within four months of his marriage.[26] Several responses from other NGOs indicated that marriage and family break-ups occurred when either spouse, but particularly the woman, was diagnosed with leprosy.[27]

38. Discrimination at school, particularly against children whose parents have had leprosy was also cited as a problem by several NGOs.[28] In China, for example, a primary school had refused to accept 30 children, although they had provided medical certificates. The parents of some of those children were also against their enrolment because their own parents or grandparents had been affected by leprosy, but mainly because of fear of discrimination.[29] In India, a nursing student was recently discriminated against at college when she showed early symptoms of leprosy.[30] Some NGOs cited dismissal of workers on the grounds of having had leprosy.[31]

39. In the Democratic Republic of the Congo, persons affected by leprosy did not have the right to marry because it was believed that leprosy was transmissible and a curse from God. Moreover, persons affected by leprosy were not allowed to bathe in the same water as other healthy people and were considered an economic burden on their family because leprosy was considered to be an incurable disease.[32]

40. In India, persons affected by leprosy were still discriminated against in the health sector. Two cases were cited of hospitals in Delhi denying admission to persons affected by leprosy, which had led to the death of the patient in one case.[33] A case of rejection and mistreatment by a hospital of a person affected by leprosy was also mentioned in Indonesia.[34]

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[24] Responses from Netherlands Leprosy Relief-Brazil and MORHAN (Brazil).
[25] Response from The Leprosy Mission-Nepal.
[26] Response from Amar B. Timalsina (IDEA-Nepal).
[27] Responses from IDEA-India, FAIRMED Foundation (Sri Lanka) and The Leprosy Mission-Niger.
[28] Responses from The Leprosy Mission-Nepal, MORHAN (Brazil), The Leprosy Mission-Niger, GPDL (Indonesia), IDEA-India, HANDA (China) and CORSOHANSEN (Colombia).
[29] Response from HANDA (China).
[30] Response from IDEA-India.
[31] Responses from Netherlands Leprosy Relief-Brazil, FAIRMED Foundation (Sri Lanka), The Leprosy Mission-Nepal, IDEA-Nepal and The Leprosy Mission-Niger.
[32] Response from FOKAD (Democratic Republic of the Congo).
[33] Response from The Leprosy Mission Trust (India).
[34] Response from GPDL (Indonesia).

41. Several NGOs indicated that discrimination with respect to the economic, social and cultural rights of persons affected by leprosy and their family members was more pronounced in the case of persons with visible deformities.[35]

42. In India, laws have been enacted to ensure that the rights of persons with disabilities also applied to some categories of persons affected by leprosy, but it was difficult to exercise those rights because of the scope and limitations of the benefits.[36]

43. Most of the NGOs indicated that there was an overall lack of measures by Governments to address the economic, social and cultural rights of persons affected by leprosy and their family members. They stressed the importance of issuing policies and laws that addressed the specific needs of persons affected by leprosy so as to ensure the exercise of their rights in that respect. They also indicated that a host of attitudinal and structural barriers persisted in society alongside the silent acceptance of age-old norms and practices of segregation and exclusion.[37]

E. Women, children and other vulnerable groups

44. With respect to promotion and protection of the human rights of women, children and other vulnerable groups of persons affected by leprosy and their family members, almost all of the responses indicated that the relevant national legal instruments were consistent with State obligations under the relevant core human rights treaties to which they were parties and barred discrimination against such groups.

45. Several responses mentioned positive steps taken in relation to women, children and other vulnerable groups of persons affected by leprosy. In Japan, the Legal Affairs Bureau of the Ministry of Justice and its branches at the district level annually conducted various awareness-raising activities on the human rights issues faced by women, children and the elderly affected by leprosy and their family members under different themes, such as "Protect Women's Rights", "Protect Children's Rights" and "Nurture a High Regard for Elderly People". They also offered counselling services on human rights, including for women, children and other vulnerable groups affected by leprosy and their family members, investigated suspected human rights violations concerning those groups and took appropriate measures.[38] The 2009 Act on Promoting the Resolution of Hansen's Disease Issues covers women, children, the elderly and other vulnerable groups and its full implementation would ensure non-discrimination against and promotion and protection of the human rights of those groups.[39]

46. In Rwanda, persons with disabilities, including those affected by leprosy, could submit applications for all employment vacancies without discrimination. Non-discrimination in schools against children from families of persons affected by leprosy was ensured and adults affected by leprosy could also benefit from adult literacy programmes on an equal basis with other adults.[40]

47. In India, a new bill on disability containing recommendations on the reintegration of women and children with disabilities was pending before Parliament. If passed, it would go a long way in protecting the rights of women and children affected by leprosy. In addition, the proposed bill that had been recommended by the Law Commission of India would afford full protection of the rights of women, children and other vulnerable groups if implemented by the Government.[41] The National Human Rights Commission, in partnership with Sasakawa India Leprosy Foundation, organized the Young Partners

[35] Responses from IDEA-India, Lepra-Bangladesh, The Leprosy Mission-Nepal and Fontilles-Nicaragua.

[36] Response from The Leprosy Mission Trust (India).

[37] Responses from CORSOHANSEN (Colombia), FELAHANSEN (Colombia), The Leprosy Mission International-Bangladesh, Lepra-Bangladesh, The Leprosy Mission-Nepal, The Leprosy Mission-Niger, The Leprosy Mission Trust (India), IDEA-India, FOKAD (Democratic Republic of the Congo) and FAIRMED Foundation (Sri Lanka).

[38] Response from Japan.

[39] Response from the Nippon Foundation.

[40] Response from the National Human Rights Commission (Rwanda).

[41] Response from The Leprosy Mission Trust (India).

Programme to sensitize schoolchildren to leprosy with a view to stopping the stigma and discrimination faced by persons affected by leprosy and their family members.[42] The National Human Rights Commission had also conducted workshops on the topic of discrimination against persons affected by leprosy and their family members and submitted several recommendations to the Government, including on the implementation of the principles and guidelines. It was still awaiting action by the Government.[43]

48. Most of the responses from associations of and NGOs working with persons affected by leprosy underlined that, even where policies and laws, including laws for persons with disabilities that were applicable to women, children and other vulnerable groups, had been adopted, they had not always been effectively implemented, which was evidence that stigma and discrimination against women, children and other vulnerable groups affected by leprosy still prevailed. The same applied to measures taken by Governments in that respect. The importance of the need for Governments to take specific policy and legal measures to promote and protect the human rights of women, children and other vulnerable groups affected by leprosy and their family members was underlined.[44]

F. Discriminatory policies and laws

49. The responses indicated that some States had taken positive steps in repealing or amending laws that discriminated against persons affected by leprosy and their family members, including laws that provided for forced segregation and isolation of persons affected by leprosy and their family members.[45]

50. In Japan, the revised 1953 Leprosy Prevention Law was repealed in 1996, thereby putting an end to the policy of isolation and segregation of persons affected by leprosy and their family members, who have since had the freedom to choose where to live. In 2001, the Government issued a law to compensate persons who had been interned in leprosariums. The Act on Promoting the Resolution of Hansen's Disease Issues came into force in 2009. It obliges the central and local governments to implement measures for the promotion of the welfare and restoration of honour, among others, of persons affected by leprosy in order to realize a society free from discrimination, including against women, children and other vulnerable groups. The 2009 Act also provides that no person shall act in a manner that discriminates against or infringes on any rights or interests of persons affected by leprosy. Full implementation of the 2009 Act would be tantamount to the implementation of the principles and guidelines.

51. In Brazil, the last discriminatory law against persons affected by Hansen's disease was repealed in the 1990s. In 2007, a bill was passed by Parliament to provide financial support and compensation to persons affected by Hansen's disease who were living in leprosy colonies, including a lifetime public pension and access to quality leprosy-related services at all levels. Legislation to provide similar support to children who had been forcibly separated from their parents at birth in the leprosy colonies was currently under consideration. It was mentioned that 2 states in Brazil had transferred property to Hansen's disease patients, making them owners of property within the leprosy colonies and that, in another state, discussion was under way to that effect. However, that state had recently demolished public buildings and was considering relocating people from the leprosy colony to a farther region.[46]

52. Bangladesh enacted a law in 2011 repealing the Lepers Act of 1898, which isolated persons affected by leprosy from society and from their own families.[47] China repealed a law in 2011, which prohibited persons affected by leprosy from marrying; and Ethiopia

[42] Response from the National Human Rights Commission (India).
[43] Response from IDEA-India.
[44] Responses from IDEA-Nepal, FOKAD (Democratic Republic of the Congo), ENAPAL (Ethiopia), HANDA (China), IDEA-India, The Leprosy Mission Trust (India), The Leprosy Mission-Bangladesh, MORHAN (Brazil), Fontilles-India, The Leprosy Mission-Nepal, Netherlands Leprosy Relief-Mekong (Viet Nam).
[45] Responses from Japan, Viet Nam and the National Human Rights Commission (Rwanda).
[46] Responses from MORHAN (Brazil) and Netherlands Leprosy Relief-Brazil.
[47] Response from Lepra-Bangladesh.

repealed a provision in the Family Act, which previously allowed the dissolution of marriage on the ground of leprosy.[48] In Rwanda, the National Human Rights Commission participated in the review of laws tabled in Parliament to ensure that no law was passed that violated the human rights of citizens, including persons affected by leprosy and their family members.[49] In 2015, organizations of persons affected by leprosy in Nepal and other NGOs working closely with persons affected by leprosy successfully lobbied Parliament not to pass a piece of legislation that would have allowed the spouse of a person affected by leprosy to claim divorce.[50]

53. In India, one of the serious gaps mentioned by both the National Human Rights Commission and all the NGOs operating in the country was the existence of several discriminatory laws against persons affected by leprosy and their family members.[51] In that respect, reference was made to a very important step that was taken recently by the Law Commission of India, a recommendatory body to the Government of India on laws. The Law Commission issued a comprehensive report entitled "Eliminating Discrimination Against Persons Affected by Leprosy" in April 2015, which identified several discriminatory laws against persons affected by leprosy and their family members and called for such laws to be either repealed or amended by the Government or its constituent state governments.[52] Apart from the Leprosy Act, which provided for the segregation of persons affected by leprosy and their family members from the general community, several laws provided that leprosy was a legitimate ground for divorce or separation. Under the Beggary Acts of various states, among others, persons affected by leprosy were classified under the same category as persons suffering from lunacy. In general, it was pointed out that around 16 discriminatory laws against persons affected by leprosy and their family members were still in effect in India. In addition, in its report, the Law Commission included a model draft legislation entitled "Eliminating Discrimination Against Persons Affected by Leprosy", and proposed that the Government of India approve it. According to information provided in the responses, the Law Commission's report was submitted to Parliament and was awaiting adoption by the Government. The Lepers Act of 1898, among others, was repealed by the national Parliament in 2016.[53] However, it remained to be seen whether the Government would take measures to repeal or amend other discriminatory laws. Moreover, all respondents believed that if the recommendation made by the Law Commission was approved by the Government of India and implemented effectively, it would be equivalent to implementation of the principles and guidelines since, in most respects, the provisions in the bill were in line with the principles and guidelines.

54. Although India was cited as being a country that still retained several discriminatory laws regarding persons affected by leprosy and their family members, a recent study by ILEP revealed that several countries still had discriminatory laws in effect which had not yet been repealed.[54]

55. WHO launched a global leprosy strategy in April 2016, calling for action by national leprosy programmes to eliminate discrimination against persons affected by leprosy and their family members. "Zero countries with legislation allowing discrimination on the basis of leprosy" is one of the targets to be achieved by 2020.[55]

56. Most of the responses from associations of persons affected by leprosy and NGOs working with them also indicated that, although the policies and laws in their respective countries allowed persons affected by leprosy and their family members to freely choose where to live, a host of attitudinal and structural stigma and discrimination prevailed in the societies in which they lived, and the fear of being discriminated against was a significant

[48] Response from HANDA (China) and ENAPAL (Ethiopia).

[49] Response from the National Human Rights Commission (Rwanda).

[50] Response from IDEA-Nepal and The Leprosy Mission-Nepal.

[51] Response from the National Human Rights Commission (India), The Leprosy Mission Trust (India), IDEA-India, Fontilles-India, Leprosy Society-India.

[52] See Law Commission of India, "Eliminating Discrimination Against Persons Affected by Leprosy", Report No. 256 (April 2015), available at http//lawcommissionofindia.nic.in/reports/Report256.pdf.

[53] See India, The Repealing and Amending Act No. 23 of 2016. Available at http://lawmin.nic.in/ld/Act23of2016RepealingandAmending.pdf.

[54] See www.reuters.com/article/us-health-discrimination-leprosy-idUSKBN0KV27T20150122.

[55] See WHO, *Global Leprosy Strategy 2016-2020: Accelerating towards a leprosy-free world* (2016).

obstacle to the reintegration into society of persons affected by leprosy and their family members.

G. Follow-up and monitoring the implementation of the principles and guidelines

1. At the national level

57. All the responses indicated that no country had a national committee to coordinate activities relating to persons affected by leprosy and no country had formulated a comprehensive set of policies and measures in the form of national action plans, as recommended by the principles and guidelines, as a basis for following up their implementation. However, some respondents noted that, despite the absence of a specific national action plan or committee established at the national level, policies and laws had been adopted in their respective countries and, if fully implemented, they would be equivalent to partial or meaningful implementation of the principles and guidelines.[56]

58. Almost all of the responses from associations of persons affected by leprosy and NGOs working with them as well as some of national human rights institutions underlined the need for Governments to develop specific measures to implement the principles and guidelines, in particular in the form of a time-bound national action plan, and to designate broad-based stakeholder committees from the national to the community level.[57] That could then form the basis for follow-up and reporting to a designated government body on the steps taken towards the implementation of the principles and guidelines. The responses received also underlined that persons affected by leprosy and their family members, either as individuals or through their associations or NGOs and civil society organizations working closely with them, should be actively involved and consulted at all levels and stages of the decision-making process in order for the Government and other stakeholders to adequately address the prevalent stigma and discrimination that persons affected by leprosy and their family members faced and to follow up and report on the implementation of the principles and guidelines.

59. Most of the responses also indicated that there should be a designated body within the Government to coordinate the national action plan for the implementation of the principles and guidelines and highlighted Ministries of Health and national human rights institutions, in particular, in their respective countries that were already engaged or should be engaged directly or indirectly in promoting the human rights of and combating stigma and discrimination against persons affected by leprosy and their family members.

60. Many of the responses mentioned some of the priority measures that their respective Governments should take towards implementing the principles and guidelines, including promoting awareness-raising and dissemination of the principles and guidelines, repealing discriminatory laws, promoting social integration and rehabilitation of persons affected by leprosy and their family members, using appropriate and dignified language and empowering persons affected by leprosy and their family members.

(a) Promoting awareness-raising and dissemination of the principles and guidelines

61. Governments should strengthen their efforts to raise awareness about leprosy and widely disseminate the principles and guidelines throughout their respective countries, including providing information about the disease, treatment, discrimination and stigma faced by persons affected by leprosy and their family members, with their active participation and in collaboration with stakeholders within the Government and within society, such as religious leaders, human rights bodies, the media, opinion makers, among others. In that regard, the principles and guidelines should be mainstreamed in school curricula and the media should be co-opted to play an active role in eliminating discriminatory attitudes towards persons affected by leprosy and their family members and to give wider coverage to advocacy programmes.

[56] Responses from Japan, Rwanda and Viet Nam.

[57] Responses from Egypt, Rwanda and the United Republic of Tanzania.

(b) Repealing discriminatory laws

62. States should take appropriate measures to repeal discriminatory laws and to formulate and implement affirmative policies and laws that ensure the protection of the human rights and dignity of persons affected by leprosy and their family members in accordance with the principles and guidelines. Discriminatory policies and laws have reinforced the prevailing discrimination against persons affected by leprosy and their family members in all spheres of social life, in particular in the areas of education, employment and marriage.

(c) Promoting social integration and rehabilitation

63. Concerted efforts should be made to reintegrate and rehabilitate persons affected by leprosy and their family members through the promotion of programmes for those living in isolation. In that respect, support for the rehabilitation of persons affected by leprosy and their family members and provision of education for children of persons affected by leprosy was emphasized.

(d) Using appropriate and dignified language

64. The age-old misconceptions about leprosy have been reinforced by the ongoing use of inappropriate and often denigrating language to refer to persons affected by leprosy and their family members in both leprosy-endemic and non-endemic countries. The use of the term "leper" and its equivalent in other languages contributes to the ongoing discrimination faced by persons affected by leprosy and their family members. States and social groups, including the media, should use appropriate terminology when referring to the disease and persons affected by it so as to highlight the human dignity of and foster respect for persons affected by leprosy and their family members. For example, persons affected by leprosy or persons affected by Hansen's disease were considered as more appropriate expressions.

(e) Empowering persons affected by leprosy and their family members

65. One cross-cutting priority that was highlighted was that persons affected by leprosy and their family members should be considered as primary stakeholders in combating the disease and the stigma and discrimination they are faced with, and should be involved in the formulation and implementation of policies and other measures taken by States, which directly or indirectly affected their lives. That would be a crucial step towards recognizing their fundamental human rights and affirming their dignity as well as eliminating the persisting stigma and discrimination, in accordance with the principles and guidelines.

2. At the international level

66. Most of the responses received highlighted the lack of a specific mechanism at the international level to follow up and monitor the implementation of the principles and guidelines by States and other concerned stakeholders. It was suggested that an appropriate body be established within the existing international human rights system to follow up and monitoring the implementation of the principles and guidelines by States. The appropriate mechanism for following up and monitoring the implementation of the principles and guidelines should be under the auspices of the Human Rights Council, which had initiated and adopted the principles and guidelines, leading to their adoption by the General Assembly in 2010.

IV. Conclusion and recommendations

67. **The principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, which were adopted by the General Assembly in its resolution 65/215 in December 2010 upon the recommendation of the Human Rights Council, have constituted a milestone document aimed at affirming the human dignity and rights of persons affected by leprosy and their family members. However, although some States have taken steps towards their implementation, much still remains to be done by both States and other relevant stakeholders to ensure their full implementation and to eliminate the discrimination, stigma and ostracization faced by persons affected by leprosy and**

their family members. The efforts made to date have often been fragmented and limited to certain government sectors, such as Ministries of Health or national human rights institutions, and not taken up in a holistic or coordinated manner that involve other actors in society, including persons affected by leprosy and their family members. Indeed, owing to a lack of effective and concerted State and societal action to implement the principles and guidelines, various forms of discrimination that impede the enjoyment of their fundamental human rights by persons affected by leprosy and their family members persist in many parts of the world.

68. Although there is a certain degree of awareness of the principles and guidelines in many countries, such awareness does not seem to be sufficiently disseminated within all sectors of government at all levels or among the population at large. The principles and guidelines are also not being used as an authority for combating stigma and discrimination against persons affected by leprosy and their family members.

69. In the majority of countries, there is no comprehensive strategy or action plan or policy framework as well as a designated body to follow up, monitor and report on the measures taken to implement the principles and guidelines. However, in some countries, one or more government institutions, such as the Ministry of Health or the national human rights institution, have taken fragmented actions to follow up the implementation of some aspects of the principles and guidelines. Moreover, full and meaningful participation of persons affected by leprosy and their family members at all levels of the decision-making process and in activities on matters that directly or indirectly impact their lives, including in following up the effective implementation of the principles and guidelines, seems to be lacking in most countries.

70. Although no specific discriminatory policies and laws were pinpointed, such policies and laws still exist in many countries and they should be reviewed and modified or repealed as necessary. Such policies and laws are not limited to leprosy-endemic countries, but also exist in non-endemic countries where leprosy is considered very rare and a "forgotten" disease. Affirmative policies and laws that provide specifically for measures to eliminate stigma and discrimination against persons affected by leprosy and their family members and that promote social inclusion of such persons in line with the principles and guidelines are lacking in most countries.

71. Inappropriate and offensive language is still used to refer to persons affected by leprosy in both leprosy-endemic and non-endemic countries. This is sometimes perpetuated by the media and in popular culture in some countries.

72. At the international level, there is a clear absence of a specific mechanism within the human rights machinery to follow up, monitor and report on measures taken and progress made towards the effective implementation of the principles and guidelines. The importance of establishing such a mechanism at the international level, preferably within the human rights system, to follow up, monitor and report on measures taken by States towards the effective and full implementation of the principles and guidelines was highlighted.

73. Based on the above findings, the following recommendations are proposed for the wider dissemination and effective implementation of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members.

A. At the national level

74. States and relevant government institutions at all levels should strengthen, promote and facilitate awareness-raising campaigns and widely disseminate the principles and guidelines as the main benchmark in the fight to eliminate stigma and discrimination against persons affected by leprosy and their family members. This should be done in collaboration with all relevant actors, such as organizations representing persons affected by leprosy and their family members, medical practitioners, educators, religious and community leaders, public figures, opinion makers and the media. In that respect, sustained and proactive public education and awareness campaigns should be conducted in order to dispel persisting myths and superstitions about leprosy, including in countries where leprosy is not a prominent

issue. Mainstreaming leprosy in school curricula and providing information in the media about advances in the treatment of leprosy and that fact that leprosy is not easily transmissible nor infectious once treated is also important.

75. States should review and identify national policies, laws and practices that may engender stigma and discrimination against persons affected by leprosy and their family members and amend or repeal such discriminatory policies and laws. States should also consider developing policies and laws that prohibit any acts aimed at discriminating against or isolating or excluding persons affected by leprosy and their family members, in line with the principles and guidelines.

76. States should designate an appropriate body and establish a national committee comprising all relevant stakeholders, including persons affected by leprosy and their family members, to follow up and monitor the implementation of the principles and guidelines. An existing institution such as the national human rights institution, whose mandate is principally to ensure the promotion and protection of human rights of all persons within its jurisdiction, or the Ministry of Health that conducts the national leprosy programme may be considered as viable options to coordinate, follow up and monitor the actions and measures taken by government entities at all levels.

77. States should ensure and support the full and meaningful participation of persons affected by leprosy and their family members, including women, children and other vulnerable groups, at all levels of the decision-making process on matters that have a direct or indirect impact on all aspects of their lives. That would send a powerful message that their human dignity and rights are recognized on an equal basis with others and would contribute to eliminating the social stigma attached to leprosy. The slogan "Nothing for us, without us" should be respected by all States concerned.

78. States should ensure that appropriate and respectful language is used by all segments of society to refer to persons affected by leprosy, or Hansen's disease, and their family members. In particular, the use of the term "leper" or its equivalent in other languages should be avoided at all costs, as it connotes marginalization and rejection by society and also discourages those affected from seeking treatment in a timely manner.

B. At the international level

79. Discrimination against persons affected by leprosy and their family members continues to exist in various forms in many countries. The principles and guidelines for the elimination of discrimination against persons affected by leprosy confirm and build upon the core principle of non-discrimination enshrined in international human rights law and constitute a benchmark for upholding the human rights of persons affected by leprosy and their family members. They represent the standard to be upheld by States in assuming their responsibility to prohibit all forms of discrimination against persons affected by leprosy and their family members. The centrality of the principles of equality and non-discrimination in international human rights law and the adoption of the principles and guidelines by the United Nations human rights machinery and the General Assembly make them authoritative standards against which to measure States' responsibility towards persons affected by leprosy and their family members.

80. Owing to the multiple forms of discrimination and violation of the human rights of persons affected by leprosy and their family members and in order to address their specific needs in terms of access to health care, education, employment and reintegration and rehabilitation into society in a holistic manner, it is recommended that a specific mechanism be established within the United Nations human rights system to address the issue and to encourage States and other relevant actors to implement the principles and guidelines. The mechanism should also be mandated to follow up, monitor and report on measures taken and progress made by States towards the effective implementation of the principles and guidelines.

81. Although existing special procedures address many aspects of the human rights of various groups, none addresses the human rights issues concerning persons affected

by leprosy and their family members. It is therefore highly recommended that a special procedure be created under the auspices of the Human Rights Council to examine the human rights situation of persons affected by leprosy and their family members and to follow up, monitor and report on measures taken and progress made by States in the effective implementation of the principles and guidelines.

82. **In conjunction with the proposed creation of a special procedure mandate, awareness-raising activities should be continued within the United Nations human rights forums in order to promote the wide dissemination and to deepen the understanding of the principles and guidelines in States and all relevant stakeholders with a view to creating a conducive environment in which a special procedure mandate holder could play a pivotal role towards the effective implementation of the principles and guidelines. In that respect, it is recommended that the Human Rights Council encourage OHCHR, in cooperation with States, relevant international organizations such as WHO as well as concerned NGOs, to organize seminars, conferences and side events on leprosy and leprosy-related discrimination and ensure substantial active participation by persons affected by leprosy and their family members.**